

Research Matters

NEWSLETTER AUTUMN 2018
THE NHS AT 70

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RESEARCH SUPPORT

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Contents

- 02 FIRST THOUGHTS**
Lynis Lewis on an inherited cause for pride
- 04 FUTURE OF RESEARCH**
Dame Anne Johnson on Health 2040
- 06 TALE OF AN NHS TIMELINE**
Seventy years of being the best
- 08 AN AGE-OLD ENEMY**
Rob Howard on dementia care
- 10 HARD ROAD TO REHAB**
Helen Killaspy on 'virtual asylums'
- 12 THE SEXUAL REVOLUTION**
Claudia Estcourt on changing attitudes
- 15 OUT OF HARM'S WAY**
Young people and mental health
- 16 THE CINDERELLA SCIENCE**
Anne Lingford-Hughes on addiction
- 18 PICTURE OF HEALTH**
Life-saving power of clinical trials
- 19 TRAINING OPPORTUNITIES**
- 20 PROJECTS RECRUITING**

First Thoughts...on 70 amazing years

The roots of the pride I still feel when I tell people that I work in the NHS can be traced precisely to two events that happened within a fortnight of each other 70 years ago.

Arguably the most important social change in the history of the UK occurred on 5 July, 1948, when health secretary Aneurin Bevan visited Park Hospital in Manchester to launch his hugely ambitious “brain child” – the National Health Service.

Just before that, on 22 June, the Empire

Windrush docked at Tilbury in Essex, bringing desperately-needed people from the West Indies to help in the rebuilding of post-war Britain.

Many of those new arrivals and the people who followed went to work in the NHS – including my mum, Marjorie, who arrived from Montserrat in 1955 and started her midwifery training, retiring from the National Hospital as a theatre sister in 1992.

She was, and still is, my inspiration for working in the NHS – even though I didn’t follow her into nursing. I chose instead to go first into social work, before deciding to switch to the crucial area of research.

Hopefully, this newsletter edition marking the 70th anniversary of the NHS will illustrate how important research has been, and will continue to be, in improving the quality of healthcare.

The life-changing and life-saving advances it has brought about over those 70 years have been nothing short of amazing ([NHS Timeline](#), Page 7).

The UK is very good at research



Lynis Lewis's mother, pictured centre in the top row, during midwife training in 1955, and on her retirement as a theatre sister from the National Hospital in 1992.



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“My mother was, and still is, my inspiration for working in the NHS”

– Lynis Lewis,
Service Director, Noclor
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and features prominently on the international stage, but the best work we do is when we collaborate nationally and internationally.

High-impact research is not done in isolation, and that is why Brexit presents a real threat of damaging the UK’s scientific community and our research capabilities.

Research drives economic growth, improves health and people’s quality of life, but there is still so much more to do, as set out in an overview and look at the future of research by [Dame Anne Johnson](#) (Page 4), professor of infectious disease epidemiology at UCL and chair of the Academy of Medical Sciences “Health of the Public 2040” working group.

In these cash-starved times, when there is the constant clamour for efficiencies and savings, well-designed clinical trials are the best way to make sure large amounts of money are not wasted on useless or even harmful treatments and therapies while effective ones are neglected. They are fundamental to improving healthcare, and it is a marker of a quality service when patients are involved in research.

There are demands for parity of esteem for mental health, and rightly so, but this must extend to research as well.

In an era of unprecedented pressures on the NHS, exacerbated by a rapidly ageing population, [Rob Howard](#) (Page 8), UCL

professor of old age psychiatry, welcomes the gradual destigmatising of dementia. However, he sounds a warning that strained resources are affecting quality of care.

[Professor Helen Killaspy](#) (Page 10), consultant psychiatrist for the Islington community rehabilitation team, outlines a pathway to help people with complex psychosis to live successfully in the community – but fears that long-term hospitalisation is trapping people in private sector “virtual asylums”.

One area that has changed beyond all recognition over the last 70 years is in the attitudes and approaches to improving sexual health. [Claudia Estcourt](#) (Page 12), clinical

professor of sexual health and HIV, also airs concerns about lack of funding and how it undermines the improvements in attitudes.

The pressures on young people are very different from what they were back in 1948. Why are so many more now reporting mental health problems, and why are so many self-harming? Resources are urgently needed for research into the underlying causes (Page 15).

Addiction is another area that has seen major treatment advances as a result of research. [Anne Lingford-Hughes](#) (Page 16), professor of addiction biology at Imperial College London, explains the importance of understanding the causes of addiction, and how it is treated as a “Cinderella science”.

And finally, if there are still any doubts about the **power of research**, consultant occupational therapist Suzie Willis (Page 18) gives a moving account of how clinical trials led by inspirational oncologist Dr David Chao at the Royal Free Hospital, Hampstead, helped to save the life of her husband.

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Making research everybody's business

Appliance of alliances can create a healthier future

Dame Anne Johnson, professor of infectious disease epidemiology at UCL and chair of the Academy of Medical Sciences working group on the health of the public in 2040, sets out the crucial links between research and healthcare

The way we practise medicine has undoubtedly been revolutionised by research initiatives such as the international Cochrane Collaboration, established in 1993 to conduct systematic reviews and guide clinical practice – together with much-improved, evidence-based trials – for medicines and other preventive interventions.

The National Institute for Health and Care Excellence (NICE), set up in 1999 to decide when

the evidence is good enough for us to move forward with a new treatment, also strengthened this revolution.

And, nowadays, we have a much stronger alliance in the UK between the research community and the NHS, thanks to the establishment in 2006 of the National Institute for Health Research (NIHR), which looks at how we can invest money in the NHS for research in a more focused and high-quality way.

Developing transdisciplinary research capacity and optimising the research environment for a healthier, fairer future were key aims of the Academy of Medical Sciences working group that I chaired, and which produced the 2016 report **Improving the Health of the Public by 2040**.

One of the major developments of the last few decades has been HIV treatment. When I came into medicine in the late 1970s, there was no HIV epidemic in human populations. The first cases of Aids were

described in the 1980s, and I had the job in 1987 of helping design the first Aids ward in London, at the Middlesex Hospital.

At that time, the young men admitted to the ward died on average within six months of diagnosis. So it is extraordinary that we moved from what was a frightening, untreatable disease with an unknown cause to identifying the virus and, within little more than a decade, having effective antiviral treatments that are now rolled out worldwide.

The Aids epidemic also had important social consequences. To some extent, the gay community forced a dialogue between patients and professionals that enabled people to be engaged in a more egalitarian relationship about how we negotiate the management of disease. Unfortunately, we haven't been able to stop the epidemic or develop a vaccine, which was the great hope of the 1980s.

The issues around HIV have helped reduce stigma about the way we view sex and sexuality. Over my career, there has been a great deal of

investment in sexual health strategy and services. But, very regrettably, there is now a crisis in these services due to disinvestment since they were moved outside the NHS into local authorities. It has been a serious step backwards.

The approach to mental health has become much more enlightened over the years. When I was training in medicine, 30 years ago, there were still large Victorian asylums with massive inpatient facilities where people could be kept for years, even for their lifetime.

We now have more treatments at our fingertips, and the development of cognitive behavioural therapy (CBT) and community services have been very important, but there are real concerns about the quality of mental health services. The chief medical officer and others emphasise that we should treat mental and physical health equally, but we've still got a long way to go.

Mortality from cardiovascular disease has been reduced, and we have made enormous strides in the quality of cancer therapy, and chemotherapy in particular – although the UK is



still behind some other European countries in cancer survival and detection.

Extraordinary advances in our understanding of the genetics of cancer have meant we are able to use more personalised treatments, including immunotherapies, which may be much less toxic than some less specific cancer therapies that still have terrible side-effects.

The remaining challenge for cancer within the NHS is early detection. Screening programmes

mean we are better at detecting breast, bowel and cervix cancer; while we are expecting big reductions in cervical cancer rates due to the development of the human papilloma virus (HPV) vaccine.

Vaccination has been extremely important. Since the 1940s, it has led to a massive reduction in childhood diseases and infectious diseases, such as measles, mumps and rubella, and has eradicated smallpox.

One of the main challenges ahead is presented by our ageing population with multi-morbidities. Dementia and social care are going to be major issues, and we need to encourage compressed morbidity – in other words, people not just living for longer, but having more

healthy years.

The NHS has a part to play, but so do factors such as social services, social interventions, good pensions, good diet, exercise programmes, work for older people who want to go on working, and all those other professions allied to medicine and social care that are an important part of a strategy for the elderly.

We are also seeing increasing rates of obesity

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“We can use our NHS resources effectively if we integrate preventive and public health interventions”

– Dame Anne Johnson



Continued from previous page

in young children, and that's going to lead to such things as type 2 diabetes, musculoskeletal problems, and mental health problems.

The origins of the epidemic lie with social inequalities, how food is sold and manufactured, exercise, built environment and transport. We need the integration of research programmes that recognise the multi-system nature of many health problems, which we can't tackle without considering the socioeconomic environment.

We are in the midst of a digital and information revolution that is equivalent to the industrial

revolution – and it is vital that the NHS adapts.

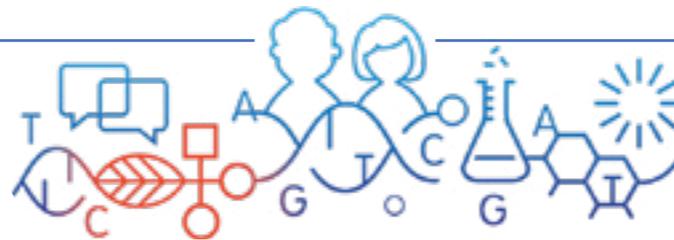
I'm involved with the Topol review, named after Eric Topol, who wrote a book called *The Patient Will See You Now*, which is about how the digital revolution has the potential to transform the way we practise medicine.

Imagine how marvellous it would be if we had integrated, accessible patient records and more remote consultation; we wouldn't waste so much time and energy on repeat investigations or failing our patients due to lack of communication.

Thanks to the web, people can be more engaged with their health – provided they have

the ability to use the internet. Many patient groups are beginning to take the power into their own hands and are looking at how services are delivered. And there's been a rise in "citizen science", where people with rare diseases are identifying and sharing information with the health service and others.

Genomics, aligned with good patient data, allows us to put together what we know about the genes with how they're manifested in the



illnesses they cause. In theory, this should enable us to practise medicine that takes account

not only of the social factors and the way diseases express, but also our genetic predispositions.

I'm hoping we'll see far more consultations being conducted remotely, on Skype and mobiles. We're developing diagnostics that can be used remotely for infectious diseases, but, if we're going to reap the benefits, a huge investment is needed to get the workforce and technology up to speed.

There have been numerous reports about the unsustainability of the NHS, but we can use our resources effectively if we integrate preventive and public health interventions.

And we must take into account what I call the reduction of modifiable risks. If somebody's got high blood pressure, high cholesterol, is overweight, doesn't exercise and has genetic risks, or even just one of those things, we can make reasonable predictions about what their risk of heart disease is and what they can do to reduce it.

Some factors can be reduced by medical interventions such as blood pressure tablets or statins,

and some reside with aspects of people's lives such as employment, smoking and diet. We need to look at how we manage health in the round.

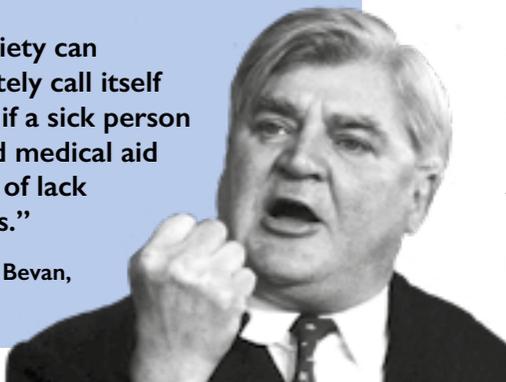
In each generation, some secretary of state will say, "We must invest more in prevention and public health." But we never do. Sadly, the NHS is not really about health, it's about crisis management.

We need a longer-term vision for how we invest. That is politically difficult because of the short-termism of governments, but it is crucial that health is thought about as a societal good, and is seen as an outcome across government – not just within the Department of Health.

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"No society can legitimately call itself civilised if a sick person is denied medical aid because of lack of means."

– Aneurin Bevan, 'father' of the NHS



TIMELINE OF CHANGE

- 1948:** The NHS is inaugurated on 5 July.
- 1951:** Bevan resigns from the cabinet after it votes to bring in charges for dental care, spectacles and prescriptions.
- 1952:** Cambridge University scientists Francis Crick and James Watson discover the molecular structure of DNA.
- 1954:** Link between smoking and lung cancer established by British scientist Sir Richard Doll.
- 1958:** Vaccinations for polio and diphtheria launched for children under 15.
- 1960:** UK's first kidney transplant carried out at Edinburgh Royal Infirmary.
- 1961:** Contraceptive pill becomes widely available.
- 1962:** Health minister Enoch Powell's Hospital Plan criticised for splitting NHS into three parts – hospitals, general practice and local health authorities.
- 1967:** Abortion Act passed, legalising the ending of a pregnancy up to 28 weeks of gestation.
- 1968:** Polio and diphtheria jabs offered to under-15s.
- 1968:** UK's first heart transplant carried out at London's National Heart Hospital.
- 1968:** Sextuplets born at Birmingham Maternity Hospital after British woman receives fertility treatment.
- 1972:** CT scans come into use (MRI scanners not introduced till the 1980s.)
- 1978:** World's first test-tube baby born as a result of pioneering research by gynaecologist Patrick Steptoe and physiologist Robert Edwards.

- 1979:** First successful bone marrow transplant on a child takes place at Great Ormond Street Hospital, London.
- 1980:** Keyhole surgery successfully used for first time, to remove a gallbladder.
- 1983:** A new Mental Health Act addresses assessment, treatment and rights of people with a mental health disorder.
- 1986:** Biggest public health campaign in history launched to educate people about the threat of Aids.
- 1987:** First heart, lung and liver transplant carried out at Papworth Hospital, Cambridge.
- 1988:** Breast cancer screening introduced for women over 50.
- 1991:** First NHS trusts established after health secretary Kenneth Clarke introduces the NHS internal market, creating the split between health "purchasers" and "providers".
- 1994:** NHS organ donor register set up to co-ordinate supply and demand.
- 1998:** Launch of NHS Direct, nurse-led service providing health advice over the phone



- 2002:** Primary care trusts set up to improve administration and delivery of healthcare at local level.
- 2003:** Labour government introduces A&E target times.
- 2006:** Smoking banned in enclosed public places in Scotland, Wales, Northern Ireland (England in 2007).
- 2006:** Government establishes National Institute for Health Research (NIHR), now Europe's largest national clinical research funder.
- 2008:** Patient choice introduced in England, ending tradition of going where a GP decides.
- 2009:** New Horizons programme launched to improve adult mental health services in England.
- 2009:** NHS Health Check introduced for adults in England aged 40 to 74.
- 2011:** Coalition government's health and social care bill, introducing GP-led clinical commissioning groups, denounced by some doctors as "the end of the NHS as we know it".
- 2012:** First hand transplant operation in the UK carried out at Leeds General Infirmary.
- 2013:** A 30-month public inquiry into deaths at Mid Staffs NHS foundation trust from 2005-09 leads to initiatives to improve care and reduce avoidable mortality.
- 2014:** NHS England publishes Five Year Forward View on sustainability at a time of rising demand, caused mainly by the ageing population.
- 2016:** Public Health England launches One You nationwide campaign to address preventable disease in adults.
- 2017:** Government abolishes student nurse bursary in England.



Making research everybody's business

Burden of fighting to overcome an age-old enemy

Rob Howard, professor of old age psychiatry at UCL and honorary consultant with Camden and Islington NHS Trust, explains how increasingly strained resources are affecting the quality of dementia care

Seventy years ago, dementia was a stigmatised and shameful diagnosis. It would have been referred to as senile decay, and feared in the same way as schizophrenia or major mood disorders. You kept very quiet if someone in your family had dementia.

When I first became a psychiatrist, in the late 1980s, I'd occasionally have to go to see a patient in one of the old asylums that were still open

around London. Some were like mini-cities with thousands of patients – most of whom had spent their entire adult lives in hospital.

There were also large numbers of people with dementia who were looked after on long-stay psychogeriatric wards.

What they had in common was that the patients certainly didn't get personalised care, and I can remember as a young doctor being frightened by the horror of this.

Although dementia care is far from perfect nowadays, the most important development is that people are supported to go on living in their own homes.

However, this means that families are carrying what can be a heavy burden of care, and they are often understandably bitter about the quality and quantity of support they receive from local authorities and the NHS.

Local authorities' social services budgets have suffered over the last 10 years and, unfortunately,

services for older people have taken an unfair hammering. This places an extra burden on the health system.

One big positive is that the stigma of

dementia is being addressed. There is now much more open conversation about it, compared even with 10 years ago.

We are also now recognising and diagnosing about 75% of people with dementia, and that's a huge achievement. Unfortunately, although we have drug treatments that make very modest improvements in the symptoms of dementia, we still have nothing that can affect the course and decline.

The government and charities – the Alzheimer's Society and Alzheimer Research UK – have made major financial investment in a national Dementia Research Institute, based at UCL, to accelerate the development of new treatments.

Because we're better at recognising it, there has been an improvement in the care of people who've got dementia along with other conditions.

For example, if you have unrecognised dementia and you suffer a heart attack and go into hospital, you are likely to have a difficult time because no one will appreciate your need to have things explained or why you may appear uncooperative.

Hospitals and community services have become much more dementia-friendly places, and research by my UCL colleague Gill Livingston has developed simple interventions to reduce distress and depression in people who care for family members with dementia.

The great disappointment from the 30 years that I've been working in this field has been the failure of treatments to stop or slow the progression of dementia. More than 200 different drugs have been tested, and all have failed.

The frontrunners at the moment are those

that raise [induce the production of] antibodies against the amyloid protein that is linked to Alzheimer's disease. A drug called BAN2410 is the most likely to appear on the treatment scene, based on the latest data to be released, but past experiences mean it wouldn't surprise me if further trials cast doubt on its efficacy.

When treatments that work against Alzheimer's disease do appear – and I am confident that this will eventually happen – we'll all have work to do to convince the NHS that this represents a priority for funding.

There are currently 850,000 people in the UK living with dementia and, as the population gets older, that will quickly turn into 2 or 3 million.

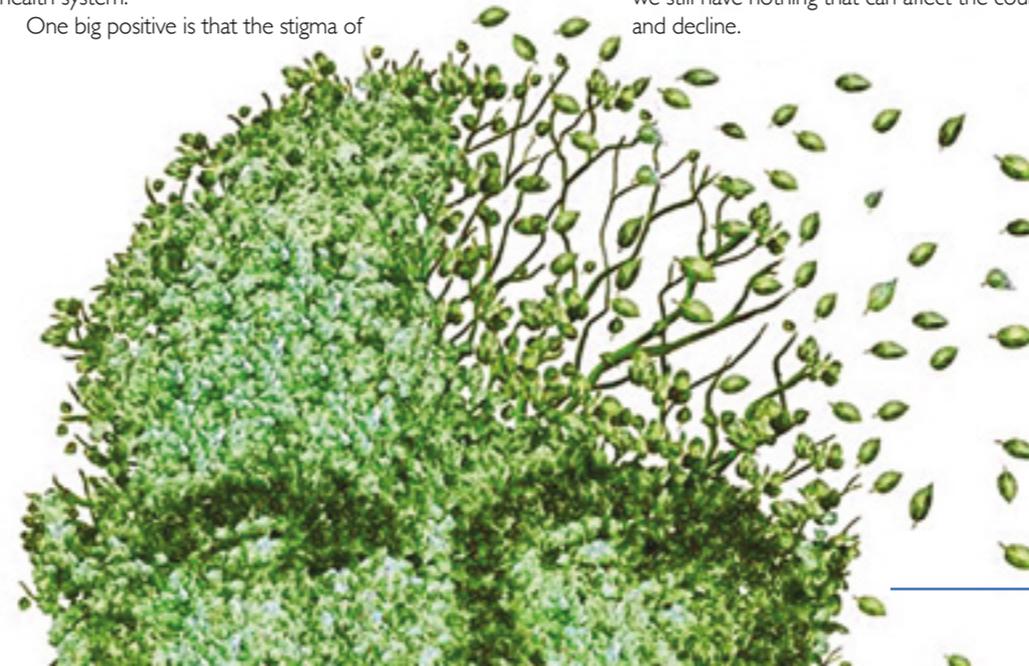
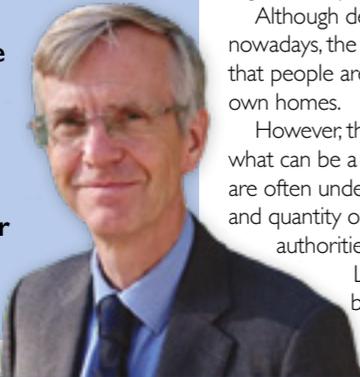
It is definitely an exciting and positive time to be working clinically in the field and to be involved in research. However, there's so much still to do, and we have to ensure that the advances being made are not reversed because of shortage of resources or because older people aren't seen as a priority for investment.

Money is beginning to flow into research now, but more is needed to expand and develop clinical services. We can't work magic if we're not given the staff and the resources to build and to keep things going.

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“We have to ensure that the advances being made are not reversed because older people aren't seen as a priority for investment”

– Rob Howard



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Rehab's pathway to recovery faces 'virtual' threat

Helen Killaspy, professor of rehabilitation psychiatry at UCL and consultant psychiatrist for the Islington community rehabilitation team, reveals her hopes and fears for services to help people with complex psychosis

Nobody would dispute that we are a million miles away from the times when people were locked away in asylums. But while we have moved forward since the days when there was no sense of hope for recovery or discharge, we must also sound a warning about taking backward steps.

The level of cuts to NHS rehabilitation services to enable people to live successfully in the

community means a kind of "virtual asylum" has developed, where people with complex needs are sent off to a bed in the private sector – on average, 40km from their home, but sometimes hundreds of kilometres away.

The loss of contact makes it very difficult to work with them in a graduated way and facilitate their discharge back into the local supported accommodation pathway, so they tend to get stuck in these "out of area" hospitals.

My research focuses on people with complex psychosis – those with illnesses such as schizophrenia and who often have additional problems that have complicated their recovery. During the 15 years I've been working as an NHS consultant, this group has become increasingly marginalised from policy and alienated from appropriate local service provision.

A growing focus on more specialist sub-groups – such as people with a particular diagnosis or at a certain stage of recovery – has been to the detriment of people

with complex psychosis, who tend to need long-term services.

Understandably, there has been a drive to minimise the time people spend in more expensive services, so those who have longer-term and very high support needs tend to be the victims of policy that likes to focus on people who get better:

The decisions about service investment plans for the more complex group get passed between local authorities and NHS clinical commissioning groups. When you're talking about very expensive people, that argument gets a lot tenser.

There is another bias. A lot of investment and focus is on getting in early, treating people's depression before they start going off sick from work, getting people at the earlier stage of psychosis to prevent long-term effects. It's right to do this – but not everyone will get better if you get in early.



accommodation services that work together to enable people to recover and live successfully in the community.

The providers of the first components of this system are the NHS; local authorities (which commission the third sector) provide the latter. Our research has involved developing tools to assess the quality of these services, to understand the aspects of treatment and care that are most effective for people at the different stages of their recovery.

The cuts to NHS rehabilitation services across the country mean a lot of trusts don't have a rehabilitation service at all – yet people with very complex problems are, of course, still being admitted to hospital when they break down in the community.

The latest Care Quality Commission (CQC) data suggests that more than half of the rehabilitation beds in the country are provided in the private sector – where there may also be a financial disincentive to discharge people.

This has been allowed to happen despite evidence from our research and other researchers that when you have a local whole system rehabilitation pathway, you can enable the vast majority of people with complex needs to

achieve and sustain community discharge. The rehabilitation world is busy campaigning and using the evidence to do whatever we can to draw attention to the need for local reinvestment in these services.

I'm the CQC's national adviser for mental health rehabilitation and was brought in to some meetings with the former health secretary, Jeremy Hunt, on this topic. He was keen to get money back into local rehabilitation and supported accommodation services, but it remains to be seen if there'll be the same support from his successor.

There is also a NICE guideline currently being developed for mental health rehabilitation that I am topic adviser to, and which should really help push back against some of the poor decision-making of recent years.

The staff who are attracted to working in rehabilitation services are fantastic, almost a special breed of mental health professionals. They enjoy working with particularly complex and interesting people, giving them specialist treatment and support over a long period of time to ensure they can live in as socially-included and independent a place as possible.

That ethos hasn't changed, despite the challenges to local services.

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"This group has become increasingly marginalised from policy and alienated from appropriate local service provision"

– Helen Killaspy



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Resources needed to keep social revolution on track

Claudia Estcourt, clinical professor of sexual health and HIV at Glasgow Caledonian University and CNWL NHS trust, and honorary professor at UCL, on how lack of funding undermines improvements in attitudes

There have undoubtedly been huge changes in social and sexual attitudes and behaviours, which we are able to track very clearly thanks to documented evidence in the once-a-decade National Survey of Sexual Attitudes and Lifestyles led by UCL

In the 1960s, it was well recognised that the advent of the oral contraceptive pill changed people's behaviour by making it possible to have

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“The next wave of change is how technologies have altered our sexual and social networks and behaviours”

– Claudia Estcourt



sex without fear of pregnancy.

Subsequent to that, there have been changes in societal attitudes to homosexuality, both male to male and female to female – most evident in the 1967 decriminalisation of homosexuality between men over the age of 21 in the UK.

We are now accumulating evidence on the next wave of change – how technologies have altered our sexual and social networks and behaviours.

The change I am expecting to see is how social media has pushed us in a slightly different direction, from an overall liberalisation of attitudes about sex to a very quick and easy availability of partners through “dating” apps.

The major shifts within sexual healthcare can be split up into attitudinal, behavioural, technological and pathogens (that is, the bugs).

In the 1980s, the threat of HIV made people take fewer risks because it was the way to prevent transmission of a

fatal infection. Now we are accruing data on the use of pre-exposure prophylaxis (PrEP), a pill taken before sex by people at high risk of HIV.

In my clinic in Scotland, we provide PrEP as a routine service and not just as part of a trial. My feeling is that we are going to observe greater risk behaviours in our community of men who have sex with men, who quite rightly know that they are protected from HIV and perhaps aren't so concerned about the consequences of treatable STIs.

Although it is a huge positive that we're protecting these men against HIV, we are yet to solve what we think will be an issue with an increase in associated bacterial STIs.

The vaccine for the human papilloma virus (HPV), an infection passed between people through skin-to-skin contact, is a huge success story.

Initially, it was introduced in 2008 in England only for girls from the age of 12 (with a catch-up programme up to the age of 18) because it



was felt that it would provide enough protection for boys too – as a result of so-called herd immunity.

Last year, it was brought in for men who have sex with men, because they are at high risk of anal cancer associated with HPV, and we are absolutely delighted that it has recently been agreed to implement routine HPV for all boys aged 11-12, starting next year. This is very good

news, but it does place more pressure on services.

At the forefront of our concerns, though, is the challenge we need to be planning for immediately: antimicrobial resistance and potentially untreatable pathogens.

Some STIs are easily transmitted, so what could be a relatively contained outbreak could have a significant public health impact if we have

infections that are extremely difficult to treat.

The press has recently heralded what they refer to as a new STI – *Mycoplasma genitalium*, commonly known as Mgen – but we have known about it for a long time. It shows a high degree of resistance or reduced susceptibility to commonly-used antibiotics.

The apocalypse we're living through in terms of sexual health funding cuts is very worrying. One of the pillars of control of STIs in the community is the availability of high-quality sexual health services, but services are in crisis due to reduced funding.

Sexual health, in terms of STI services and public health, has been funded by local government, rather than the NHS, since 2012, but demand is now far exceeding capacity – as flagged by the Local Government Association's recent plea to central government for more resources.

Across London, budget cuts have meant a 30% reduction in funding available for services, yet we know from data from Public Health England that attendances at services have increased by about 13%. We are very aware that there is a lot of unmet need, with clinics having to turn people away. Although this is

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most keenly felt in London, it is also happening in other areas of the UK. If a person cannot get into services, they cannot access the care they need or get infections diagnosed, and so transmission increases within the community.

In sexual health services, we've always been pretty good at embracing change under pressure, frequently having to find ways to deliver services more effectively and more leanly to cater for the demand.

The advent of eHealth and non-invasive diagnostics is opening up possibilities for patients to self-manage their care, which is very much along NHS strategy lines.

You can diagnose many infections from a urine test or from a vulval or vaginal swab that somebody can do themselves, and people can supply their own samples for blood testing using finger-prick tests.

However, the vast majority of eHealth innovation has been introduced without robust evaluation, which is the only way we can tell whether something is cost-effective and whether we're potentially disadvantaging those who might find it most difficult to access services.

My UCL team, working with colleagues in several other institutions, are looking at how we



might deliver complex care pathways online for patients who are digitally literate, health literate and who feel that accessing the service in this way meets their needs.

However, we have to be very careful that this isn't seen as a complete replacement of face-to-face care, because the people we worry most about are those who don't like accessing care online, might not have English as their first language, and might be very vulnerable.

Unless there are alternatives preserved for people in these groups, there is the possibility that we could widen the health divide with clumsily-introduced eHealth.

On a more optimistic level, I would hope that many more complex elements of health will be offered online – for appropriate people under appropriate circumstances – for those who are able and willing to manage elements of their own sexual health.

This could provide real advantages in terms of freeing up space for face-to-face consultations with people who might be more in need because of their medical or social complexities. However, research funding for this sort of large-scale, robust eHealth evaluation needs to be made available.

These are extremely challenging times, with sexual health services so over capacity that it is difficult even to see the people who do identify the need to access them.

It is becoming hard to resource efforts to attract people we think we could do a lot for in terms of prevention and reduction of unwanted pregnancies, and who may perceive barriers to getting our service.

That's something about which we feel tremendously uncomfortable.

Challenge of keeping kids safe from harm

The road from childhood to adulthood has always been a journey fraught with anxieties and stresses – but perhaps never more so than for today's generation.

Seventy-five per cent of mental health conditions start before the age of 18, with consequences that can be lifelong, according to research charity **MQ's manifesto for young people's mental health**.

A report published this August by the **Children's Society** on its analysis of data on 14-year-olds – taken from the **Millennium Cohort Study**, led by UCL – revealed that 22 per cent of girls and nearly one in 10 boys were self-harming.

And a report last year in the **British Medical Journal** said that self-harm reported to GPs among teenage girls under 17 in the UK increased by 68% over just three years – three times more common than among boys – and that those who self-harmed are at much greater risk of suicide.

There is concern that the pressures of contemporary culture and modern technology – such as smartphones, Instagram, Facebook

– could be exacerbating the problem in ways that would have seemed inconceivable at the time the NHS was founded.

Research has helped us to improve our recognition of mental health issues in young people, but there is still so much more that



needs to be done, according to Dr Eilis Kennedy, consultant child and adolescent psychiatrist and director of research and development at the Tavistock Clinic.

Dr Kennedy, who is also children and young person's mental health research champion for the NIHR Clinical Research Network North Thames, says: "Initiatives such as the MQ manifesto are helpful in highlighting the importance of these issues, and the relative lack of investment in research funding.

"This is starting to change as the importance of a lifelong perspective on mental health and the need to address issues early on in childhood and adolescence are increasingly recognised.

"We don't fully understand why so many girls are self-harming, and why there has been such an increase in recent years.

"That's why we urgently need more research to better understand the causes, and also how best to support young people, their families and the professionals working with them. Services are often struggling with the increased demand, and that is not helping the situation".

Making research everybody's business

'Cinderella science' of digging out addiction's roots

Anne Lingford-Hughes, professor of addiction biology at Imperial College London and consultant psychiatrist at CNWL, on exploring the neuroscience of addiction – and the damaging effect of cuts

Around the time the NHS was founded, the drug disulfiram (Antabuse) was being used to treat the serious problem of alcoholism, Alcoholics Anonymous (AA) was being formed, and methadone was in the process of being approved for use in opiate addiction. Remarkably, they are still three key elements of treatment for addiction today.

Tobacco addiction was also an issue in the

1940s – but, unlike today, smoking was being promoted as “cool” rather than seen as a public health issue. There were also problems with other drugs, such as opiates.

When I started training in the early 1990s, we generally offered opiate substitute medication such as methadone or buprenorphine to treat addiction.

Giving substitute treatment as a “harm reduction” strategy came to the fore post-1980s as a strategy to prevent the spread of HIV and hepatitis B and C, which then generally were fatal. The success of this approach means we now have addicts who have been successfully maintained on substitute drugs for many decades.

People are often surprised to learn that the novel psychoactive substances are in fact “old” compounds that have been known about for many years. A key difference is in how a chemical is used. For instance, stimulants such as amphetamines were used

by the military to help keep the troops going, and there were even adverts saying things like, “Thanks to benzedrine, we won WWII.”

We might want heroin – morphine – as a painkiller. Ecstasy and LSD, widely-used recreational drugs, have been used as therapeutic treatments and are being investigated again now. LSD was trialled as a treatment for alcoholism.

In the 1980s, the simplistic “Just say no” campaign failed to convince people to stop taking drugs because they were bad for them, but increased the stigma against those who did take them. Even now, people who supply an ecstasy tablet to somebody who then dies are still treated as criminals. Why not ask why they were taking ecstasy, and what it is about society that is causing people to seek alternatives?

We need to better manage these substances, rather than just criminalising and banning them. High-potency compounds such as spice have become a problem in recent years, but were

originally developed by pharma companies looking for better painkillers. It's all been known for decades, but now it's being used in a different way.

Understanding how the brain is affected – such as whether alcoholism is a disease – is still very contentious in some quarters, where addicts may be seen as merely “lacking moral fibre”.

What has really changed over the last few decades is our understanding about the neuroscience of addiction – that how the brain works is not necessarily about making “a drug treatment”, but instead it helps us to work out the best way to intervene. If we understand that someone is impulsive and has problems with making correct decisions, we can focus on dealing with that psychologically.

People are shocked when you tell them that 6% of the adult population is alcoholic. The associated morbidity and mortality is a huge burden on the NHS, yet we don't get equitable



funding. We are a Cinderella science. This means we are reliant on key strategies from the Medical Research Council and the NIHR. We can get funding, but there aren't that many of us in the UK working at a senior level.

Fewer people are getting training opportunities in addiction. While most people would feel that understanding schizophrenia, depression, cancer, Alzheimer's disease or physical health is worthwhile, that is not always the case with

mental health – and addiction is on the edge of that.

My hopes are that there is a reduction in the stigma, and that the dramatic cuts made to UK treatment centres are reversed. It's very hard to carry out research in some areas at the moment because the services are now outside the NHS and, therefore, outside NIHR's research infrastructure.

With novel psychoactive substances, the pace at which the chemists can make potent compounds outstrips what we can match in terms of testing, with restrictions and legalities often

making it difficult for us to look at the toxicology.

Gaming is currently another area of interest, and CNWL has just started a pilot scheme for a clinic for computer game addiction.

We also need to understand those who are at a higher risk, and how we can prevent recreational or occasional use of drugs becoming more dependent use. Despite all the work we've done to try to reduce the death rate from opiates, it is still climbing.

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NHS70

“We need to better manage these substances, rather than just criminalising and banning them”

– Anne Lingford-Hughes



Power of trials creates a clear picture of health

If anyone was ever tempted to question the power of research to improve healthcare, a quick word with Suzie Willis would soon dispel any doubts.

The photograph of Suzie, consultant occupational therapist at Central and North West London NHS Foundation, with husband Nick and dog on a 2016 holiday in the west of Ireland would not have been taken had it not been for clinical research trials.

Three years earlier, Nick's chances of surviving malignant melanoma were rated no higher than 15 per cent. But the future, so bleak back then, is now so much brighter as a result of research at the Royal Free hospital, Hampstead.

Suzie recalls that the problem began in 2010, when a mole on the back of Nick's leg "turned nasty". He was 52 at the time, cycled and walked everywhere, fit as a fiddle, and never had to take a day off from his work as an architectural photographer.

He was eventually referred to the Royal Free – under the care of consultant oncologist Dr David Chao – and subsequently had the mole surgically removed.

However, a recurring need for surgery over the next three years eventually led to a diagnosis in 2015 that the cancer was now too deep to be operated on again.

Nick was put forward by Dr Chao for the Columbus clinical trial comparing combinations of MEK inhibitor drugs. But after getting a clear scan in January 2016, by September the cancer had come back.

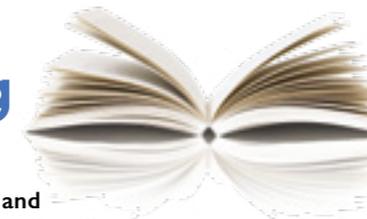
The game-changer for Nick came in summer 2016, when NICE licensed the combined use of two immunotherapy drugs – a monoclonal antibody called ipilimumab and pembrolizumab, a humanised antibody that had been clinically trialled by Dr Chao – for NHS use in the treatment of melanoma.

Nick was started on the immune therapies in November and, by January 2017, a scan showed that he was clear of cancer.

Suzie, who sees a key aspect of her OT role as being to embed the culture of research – using it and participating in it – in everyday clinical practice, says: "Dr Chao is such a wonderful man, and the power of research really is incredible. It's our future."



Pathways to training opportunities



The following sessions are being hosted by Noclor and our associates. All the sessions are free and open to all staff who have an interest in research (including doctors, dentists, nurses, research assistants) and who are working in, or are associated with, our partner trusts.

- **Good Clinical Practice in Research**

Monday, 10 December
13.00-17.00

- **Essential Skills for Conducting Effective Clinical Research**

Tuesday, 11 December
9.30-17.00

- **Informed Consent in Clinical Research**

Wednesday, 12 December
13.00-17.00

- **Principal Investigator in Research**

Wednesday, 12 December
17.30-19.30

- **Setting up and Managing the Trial Master File**

Thursday, 13 December
9.30 – 13.30

All these courses will be held at St Pancras Conference Centre, St Pancras Hospital, 4 St Pancras Way, London, NW10PE.

For information and bookings of Noclor courses, visit www.noclor.nhs.uk to download your booking form. If there is a training subject that your research staff would benefit from that we do not currently offer, please do get in touch with us at: irina.grinkova@nhs.net

Key Contacts

The Noclor Research Support team is here to help you with research. So please feel free to contact our various teams.

For queries relating to Research Management and Support:

contact.noclor@nhs.net

Funding and Finance queries:

finance.noclor@nhs.net

Looking for advice with or interested in a project in Primary Care? Contact:

primarycare.noclor@nhs.net

Keen to learn more about our free training courses, or to offer content suggestions for future Noclor publicity material? Contact:

irina.grinkova@nhs.net

If you would like to get in touch with our Service Director, Lynis Lewis, please contact:

irina.grinkova@nhs.net

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Editorial content: **Katie Shimmon**

This paper is Forest Stewardship Council certified

Projects currently recruiting

● **SUMMIT:** Screening study using low dose CT to support the development of blood tests for early detection of lung cancer. Four London hospitals have been gifted CT scanners as part of the study, which will involve 50,000 primary care patients aged 50-77 (current smokers, previously regular smokers and people with no significant history of smoking) across north and east London.. More information:

noclor.norththamescrn@nhs.net

● **CHIPS+:** A cohort study on optimising the health of young people with HIV in their transition from paediatric to adult care, focusing on participants who acquired HIV perinatally or in early life (PHIV). The aim is to study 1,500 people aged 15 years and above, the large majority of whom will have been followed up as part of the national Collaborative HIV Paediatric Study (CHIPS). More information:

mrcctu.chipsplus@ucl.ac.uk